YOU ARE NOT ALONE

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CHAIR’S MESSAGE

TEAM EFFORT

I have now had the privilege of being the Chair of Alzheimer’s Australia NSW for seven months, and in that time I have learnt many things. I have come to know about the incredible challenge provided by dementia in its size, cost and impact on individuals, families and communities. I have met people living with the condition who face each day with bravery and determination. I have seen carers who are devoted and thoughtful and absolutely loyal. And I have come into contact with so many volunteers who are generous and enthusiastic in everything they do for the cause and in support of our work.

But in this edition, I would like to pay special tribute to the staff of Alzheimer’s Australia NSW for the wonderful work that they do in support of people living with dementia and their carers. As Chairman, I have the privilege of seeing their work up close in a range of circumstances. Our counsellors are sensitive and thoroughly professional, and our educators are talented and hard working. We have Younger Onset Dementia Key Workers providing the most up-to-date care and advice to those diagnosed with dementia under the age of 65. We have staff on the Helpline, and dementia advisors and counsellors who are knowledgeable and vastly experienced. Our staff members provide excellent carer support and a welcoming approach to all who visit our offices.

And behind them and supporting them at every turn are the administrative staff – the receptionists who perform such a vital role in welcoming the outside world, our IT, the finance and accounts staff who work with such attention to detail, and our fundraising team, whose work is so critical to the delivery of our services. We have a highly proficient policy and research team, and our marketing and media efforts are of great quality and creativity.

Our staff members are ably led by our CEO The Hon. John Watkins AM, and our senior managers, who as well as managing our efforts in NSW, play an integral role in the work of the National Office. NSW prides itself in positively supporting the national effort.

We are also extremely fortunate to have a talented, capable and committed Board of Directors.

I have noticed the good morale of our staff and their deep commitment to the care of others. We are indeed privileged to have such a workforce, especially as there is so much change happening in dementia care.

Paul Robertson AM
Chair, Alzheimer’s Australia NSW

CEO’S MESSAGE

MISSED OPPORTUNITY

Despite our best efforts, this long winter federal election campaign was unfortunately largely free of discussion about aged care or dementia issues. Alzheimer’s Australia’s organisations across the country campaigned for all political sides to commit to a national dementia strategy to address what is surely one of the most significant chronic health conditions of our time.

We know that seven in 10 Australians are impacted by dementia in some way. Yet we still do not have a fully funded national dementia strategy to address this national health priority. And we are facing a future where the planned budgetary cuts to the Aged Care Funding Instrument will have a profound impact on quality of life for people with dementia living in aged-care facilities.

The lack of attention to these issues was disappointing, especially given the increase in dementia prevalence over the three-year term of the new Federal Government. In NSW alone, there will be 125,000 people living with dementia by 2019 – an increase of more than 10,000 people.

We hope that the election result will encourage the Federal Government to think very carefully about aged care and dementia policy, and we appeal to the government to reconsider those planned changes to aged-care funding.

The theme of this year’s Dementia Awareness Month, starting on 1 September, is ‘You Are Not Alone’, and you can be assured of Alzheimer’s Australia NSW’s commitment to advocating for the needs of people living with all types of dementia, and for their families and carers. We will continue to engage government at both federal and state levels to ensure a long-term, fully funded dementia strategy is implemented. It is vital that significant investment in dementia care and support leads to better outcomes for people with dementia and their families.

Dementia Awareness Month will include a wide range of events aimed to dispel myths and raise awareness about dementia and – critically – where to get help. For more information on events scheduled throughout the month, please turn to page 5.

Thank you for your continued support.

The Hon. John Watkins AM
CEO, Alzheimer’s Australia NSW
**NEWS**

**PRIZE-WINNING PROFESSOR**

Professor Henry Brodaty AO (pictured), Alzheimer’s Australia NSW Honorary Medical Adviser, was recently named the winner of this year’s prestigious Ryman Prize for his work in dementia research.

The Ryman Prize, an international award worth $250,000, recognises work that contributes to an enhanced quality of life for older people. The prize was established as the equivalent of a Nobel Prize for people working in geriatric health.

Ryman Prize juror Dr David Kerr says Professor Brodaty, who is also the co-director of the Centre for Healthy Brain Ageing at the University of New South Wales, is a worthy winner.

“We had an incredible field this year, and there were some strong contenders from all over the world,” he says. “Professor Brodaty’s nomination was a standout; his dedication and achievements are truly world-class. He is a pioneer in diagnosis and treatment of Alzheimer’s and dementia in Australasia, and his influence has been felt around the world.”

Receiving the award was an honour, says Professor Brodaty.

“We are all ageing. Older people are the fastest-growing sector of our population and mental health is the largest contribution to disease burden as we age,” he says.

“I’m absolutely thrilled to receive this award. The Ryman Prize highlights the importance of enhancing the profile of research to improve the quality of life for older people.”

**PAINT WITH A PURPOSE**

On 2 June, The Yellow House in Potts Point, Sydney, played host to an art show with a difference. The Art for Alzheimer’s event showcased 16 works donated by prominent or up-and-coming Australian artists such as Ken Done, Warwick Fuller, Swetik Korzeniewski, Charmaine Pike, Dan Kyle, Annalisa Ferraris and Lucy O’Doherty to raise funds and awareness for Alzheimer’s Australia NSW.

Painter Luisa Low, who organised the event, wanted to pay tribute to her grandfather Bruno Bellini. He passed away from Alzheimer’s disease in 2005 when Luisa was 15 years old. Luisa’s vision was not only to raise funds for Alzheimer’s Australia NSW by auctioning off the donated artwork, but also to increase vitality in aged-care homes by gifting them with some of the beautiful paintings from the art show.

Eight of the works exhibited have either been sold or are still for sale. All proceeds go to Alzheimer’s Australia NSW. The remaining works have been donated to various aged-care facilities across NSW.

The exhibition was officially opened by Alex Greenwich, NSW MP for Sydney, and Alzheimer’s Australia NSW Dementia Advocate Jacqui Louez Schoorl, who told a very moving story about her family’s experience with dementia. The event included a surprise performance by singer/songwriter Phebe Starr, who sang an a cappella version of a song written in honour of Jacqui’s father. More than $4000 was raised by the end of the night.

“We are all ageing. Older people are the fastest-growing sector of our population and mental health is the largest contribution to disease burden as we age,” he says.

“While there is not yet a cure for Alzheimer’s disease, improvements can be made for those living with the disease,” Luisa says. “It is wrong to think that nothing can be done to improve the lives of those with Alzheimer’s disease.”

“Following on from this exhibition, my plan is to coordinate an ongoing artwork donation system to aged-care homes across the country.”

"Blustery Morning" by Warwick Fuller was one of the donated artworks.
DEMENTIA AWARENESS MONTH

“You are not alone” is the message this year’s Dementia Awareness Month (DAM) hopes to spread through events aimed at dispelling myths and raising awareness about dementia. All activities will run from 1-30 September.

DAM will focus on the crucial role of education about dementia and risk reduction factors, and – most importantly – where to get help. A major media campaign is planned during September, including mainstream TV, radio, press, and social media.

The centrepiece of the month’s activities is the Alzheimer’s Australia NSW DAM 2016 lecture on 19 September. Held in Sydney, it will feature international dementia expert Dr Ron Petersen from the Mayo Clinic. Dr Petersen is a dementia research and education heavyweight, and he has been at the forefront of policy formulation and the development of a national strategy for dementia in the US. Dr Petersen will discuss the latest insights and research findings about mild cognitive impairment and dementia, along with international case studies showcasing what it takes to establish a national dementia strategy.

Here are some other can’t-miss events:
• A regional NSW DAM lecture tour: Hear and learn from leading Australian dementia expert Professor Jacqui Close, who will conduct seminars in Port Macquarie and in The Tweed.
• The Thinko! Black Tie Extravaganza: A star-studded evening of brain-testing trivia, drinks and fun to raise money for Alzheimer’s Australia NSW, featuring the likes of the ABC’s Richard Glover, and Network Ten’s Natarsha Belling and Hugh Rimington.
• Still Dementia in a Changing World: A free public forum about consumer directed care, and assistive technology and dementia, which will be held in Illawarra.
• Stories of Me: A Baptist Care professional development forum exploring how technology and creative ageing programs are being embraced to support aged-care residents who are living with a dementia diagnosis.
• Healthy Ageing and Dementia forums: Free public brain health information sessions held across the state. For more on Dementia Awareness Month events, visit: nsw.fightdementia.org.au/nsw/about-us/campaigns/dementia-awareness-month-2016-nsw Or phone: (02) 9805 0100

KNOWLEDGE IS POWER

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ANNUAL GENERAL MEETING 2016

All members and supporters are invited to attend the Alzheimer’s Australia NSW Annual General Meeting.

Date: 24 November 2016
Time: 2.30pm
Location: Vincent Fairfax Family Resource Centre, Macquarie Hospital Campus, 120 Cox’s Road, North Ryde.

The guest speaker will be Dr Shantel Duffy from the University of Sydney’s Brain and Mind Centre and the Woolcock Institute of Medical Research. She will share the latest research pertaining to physical activity and exercise for individuals at risk for or living with dementia.
A dementia diagnosis is life changing. The person living with the disease, their loved ones and carers are all affected in myriad ways. Feelings of guilt, grief, loss and anger are inevitable, and many report feelings of loneliness.

With more than 353,800 Australians currently living with dementia – including 115,000 in NSW – and an estimated 1.2 million people involved in the care of a person with dementia, it is important to know that you are not alone.

Knowing what to expect and connecting with others living with dementia can lessen the fear of the unknown, provide a better understanding of your diagnosis, prepare you for the future and take steps to help you to live your best possible life.

“If you are dealing with feelings of isolation, we want you to know that you do not have to carry the burden by yourself,” says Susan McCarthy, Alzheimer’s Australia NSW General Manager – Services. “We have developed specific programs and embraced new technology to enable more people to be able to access information and services, whatever their situation and wherever their location might be.”

A range of support, information and education options are available to help those living with dementia remain connected to their loved ones and community.

“This is available through our Living with Dementia and Better Life programs,” Susan says. “Or by joining in-person support groups. These can be made up of families, carers and friends of people with dementia under the guidance of a group facilitator. Talking with people who may be in similar situations can help.

“Through sharing your own story, other people know they are not the only ones who might be struggling; comfort and support can be found in numbers.”

Confidential counselling services for individuals or small family groups are also available for those who need it.
"The feedback we receive for our counselling services is that they provide support to both people living with dementia and their carers, confidence to deal with the challenges they might be facing and a new outlook on their lives," Susan says, adding that the opportunity to access counselling over the phone or online via Skype is an important convenience.

Likewise, regular webinars (web-based seminars) on a range of dementia-related subjects can provide helpful strategies to people living with dementia and their carers.

The estimated 70,000 Australians living alone with dementia often need more support than traditional community care packages can provide, and more flexible service delivery might be required. Alzheimer’s Australia NSW can help people living alone access support services.

For further information, call the National Dementia Helpline on 1800 100 500 or email: helpline.nsw@alzheimers.org.au
COUNSELLING
Alzheimer’s Australia NSW dementia counsellors are skilled professionals who are trained to provide confidential support, advice and practical assistance. Counselling can be delivered in several ways, including via phone or Skype.

A family conference with a counsellor is a valuable first step in making sure that everyone starts at the same level of understanding. From there, you can develop complementary support roles and work towards improving relationships to help cope with a dementia diagnosis.

Rebecca, who received counselling over the phone, says she found the service helpful.

“It gave me a new way of seeing the challenges with facing Mum’s dementia and gave me the confidence to deal with it,” Rebecca says. “I am sure it will continue to be rocky, but it gave me a window I’d not looked through before.”

For more information or to arrange counselling, call the National Dementia Helpline on 1800 100 500.

WEBINARS
Alzheimer’s Australia NSW’s webinar series is designed with family carers in mind. It offers courses and workshops including Understanding Dementia, which is an introduction to dementia, its causes and the importance of early planning. The Communication and Behaviour webinars look at the changes in communication that occur for the person with dementia and how to respond to behavioural changes. Understanding Younger Onset Dementia examines the impact of a diagnosis and increases awareness of causes, and Transitions into Care covers the practical aspects and process of selecting an aged-care facility.

John Voytas and his wife, Suzanne, accessed education through Alzheimer’s Australia NSW webinars. Following his mother’s dementia diagnosis. He says it was a good introduction to the disease and a helpful precursor before attending in-person training sessions.

“There was a lot of stress in the home,” John says. “We were new to this disease, and we wanted to know more so that we could assist my mum, who was living with us.”

For more information, visit: https://nsw.fightdementia.org.au/nsw/education-and-consulting/education-and-training
IT’S TIME TO END THE DEMENTIA STIGMA

PROFESSOR HENRY BRODATY AO AND PROFESSOR PERMINDER SACHDEV AM, CO-DIRECTORS, CENTRE FOR HEALTHY BRAIN AGEING (CHEBA)

Dementia is not contagious. Dementia is not dangerous. Yet all too often, people with dementia and their families feel isolated after the diagnosis. Friends stop visiting. Acquaintances are awkward in their conversations. Families are uncertain how best to help.

Many people keep their diagnosis a secret for fear of being shunned or excluded from normal activities. In some cultures, dementia carries a special stigma, and families worry that their children might be disadvantaged if word spreads that one of their parents has Alzheimer’s disease or a similar condition.

The situation with cancer 40 to 50 years ago was similar. Now, we know that support can help and that dementia is a word, not a sentence. A diagnosis does not preclude positive living, loving relations and joyful experiences. People with dementia can talk to others with similar conditions through their local Alzheimer’s Australia NSW office or online through the Dementia Alliance International.

Families can join Alzheimer’s Australia NSW, attend local meetings and enrol in Living with Dementia educational programs (see page 16 for details). Our research has shown that family carers who have more support from friends and families are less likely to feel burdened or depressed.

Knowledge really is power. People with dementia can understand what is happening to them and what to expect. Family carers can learn better ways to assist their loved ones, effective techniques of preventing or dealing with agitation or other behaviours, and how to garner support.

I have found it useful to encourage extended families to meet and work out strategies as to how they can best help the person with dementia and the primary care partner. Too often the responsibility falls on just one person – usually the spouse. Too often, the spouse ‘protects’ their children who are ‘too busy’ and never ask.

Reach out. Seek support. If your family or friends are uncomfortable, guide them.

Find out more about CHEBA at www.cheba.unsw.edu.au. Professor Brodaty is an Honorary Medical Advisor to Alzheimer’s Australia NSW.

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BETTER LIFE PROGRAM

After Jane’s husband, Harry, was diagnosed with dementia, Jane took part in the Better Life program run by Alzheimer’s Australia NSW.

The program is suited to carers and people in the early stages of dementia who might find it difficult to attend group support and education programs. A personal coach works with participants to help build confidence to manage the impacts of dementia and achieve wellbeing goals at their own pace. The program is designed to be flexible, accessible and individualised and can be delivered over the phone or via video chat.

“Harry and I live in the beautiful Southern Highlands, NSW. Harry was diagnosed with mild-moderate Younger Onset Alzheimer’s disease in October 2014. He was 64 and I was 51. The changes in Harry’s behaviour, the loss of family and friends, income and future plans was devastating. I felt angry, hopeless and very isolated,” Jane says.

“Societal attitudes and support align with older people living with Alzheimer’s disease and it was difficult to find specific help and information for people with Younger Onset and their carers, as many of us are working full time and/or have younger families and older parents whom we care for.

“I became involved in the Better Life program because I was desperate and needed support to navigate an avalanche of information and to juggle Harry’s needs with work and family commitments. “The program has been incredibly helpful and [my personal coach] Heather has supported me through many challenges including communication changes and feelings of isolation. I’ve found it very difficult to talk about my experiences with family and friends, as they all work and have their own families. Heather also encouraged me to use other services such as counselling, and to understand the significant role a younger onset key worker can play in our lives.

“There’s no cure for Younger Onset Alzheimer’s disease but when all hope seemed lost, at least now I feel we can find a way forward.”
A DOSE WITH THE MOST

THERE’S BEEN HYPE ABOUT A VACCINE AGAINST DEMENTIA FOR YEARS. BUT IS SUCH A THING EVEN EVEN POSSIBLE?

Excitement that a dementia vaccine might be only years away began with international research published on 1 July in the journal Scientific Reports. However, it needs to be emphasised from the beginning that this published study was only undertaken in mice, and the vaccine has not yet been trialled in humans. This study is also of interest in Australia, as the team who undertook the trial included researchers from Flinders University in South Australia.

In this multinational study, the research team trialled a variety of vaccine formulations, including one that was called a ‘dual-epitope vaccine’. This means the vaccine has an ability to produce antibodies against both Amyloid beta and Tau proteins – two proteins that accumulate in the brain, clump together and become toxic, causing disease progression.

Professor Nikolai Petrovsky, who is based at Flinders University and involved with the study, told ABC Radio “essentially what we have designed is a vaccine that makes the immune system produce antibodies and those antibodies act like tow trucks so they come to your driveway, they latch on to the breakdown protein or car and they pull it out of the driveway.”

For a dementia vaccine to be effective, the antibodies need to attach themselves to the Amyloid beta and Tau toxic protein. By doing this, the proteins become non-functioning, and ultimately means they are no longer able to cause disease progression in the brain.

This study was novel in the fact that the amount of antibodies (and other immune cells) being produced was considered high enough to minimise disease progression. The other important aspect to this study was the formulation of the vaccine. The researchers suggested they have developed a formulation that would be suitable and safe for human use.

This is certainly very promising, but what is the reality of a vaccine? The study has not yet been trialled in humans in any way, the good news is that this is now what the researchers plan on doing over the next few years during pre-clinical trials. Unfortunately, this means we don’t yet have any evidence to suggest that the vaccine has an ability to prevent disease, and this won’t be known until it can be trialled in humans.

This is also not the first time the potential of a dementia vaccine has been highlighted. Two years ago, Alzheimer’s Australia reported on the idea of a dementia vaccine and asked Henry Brodaty, Scientia Professor for Ageing and Mental Health and one of Australia’s leading dementia researchers to comment. Professor Brodaty said that an immunotherapy approach to treating Alzheimer’s disease has promised much but delivered little.

“Dale Schenk’s 1999 publication of a vaccine that reversed Alzheimer’s in mice set the dementia world agog with excitement. However, subsequent human trials were halted because of serious side effects,” Professor Brodaty said back in 2014.

The same article quoted Dr Rebecca Nisbet from the University of Queensland Clem Jones Centre for Ageing Dementia Research, who said, “Possibly what researchers need to start focusing on is combining these passive vaccination antibodies together, for example a vaccine which might target fragments of both Tau, Amyloid beta and other Alzheimer’s disease biomarkers.”

The science is progressing in leaps and bounds, and we are getting closer to human clinical trials.

Professor Petrovsky says, “If we are successful in pre-clinical [human] trials, we could be on our way to one of the most important medical developments in recent history.”

The research in this area is still progressing, and we’ll continue to keep you posted.
Another piece to the dementia research puzzle is falling into place. Researchers from the Maastricht University Medical Centre in the Netherlands have found that a leaky blood-brain barrier might kick-start Alzheimer’s disease. Their results were recently published in the journal Radiology.

**A NOVEL TOOL HAS BECOME AVAILABLE TO STUDY THE CONTRIBUTION OF BLOOD-BRAIN BARRIER IMPAIRMENT TO DISEASE ONSET AND PROGRESSION.**

In this pilot study, the researchers analysed MRI brain scans of 33 people: 16 had already been diagnosed with early Alzheimer’s disease, and 17 were classified as age-matched control participants, meaning they did not have any identified brain impairments. This type of brain scan is able to identify if blood is leaking from the brain. It then generates a map doctors can use to determine the amount of leaking brain tissue.

The blood-brain barrier is extremely important, as it separates the circulating blood from the brain and keeps brain tissue in a healthy condition. Most importantly, it regulates delivery of nutrients, blocks toxins and removes surplus substances.

“A blood-brain barrier leakage means that the brain has lost one of its key protective means, the stability of brain cells is disrupted and the environment in which nerve cells can interact becomes ill-conditioned,” says study author Dr Walter Backes from the Maastricht University Medical Centre.

The researchers found that blood-brain barrier leakage was significantly higher in people diagnosed with early Alzheimer’s disease compared to the control group.

To quantify this result, all participants underwent a mini-mental state examination (MMSE), which is a common test used to identify brain impairments. After analysing the MMSE results, the researchers found that cognitive function declined with increased leakage in the brain.

“For Alzheimer’s research, this means that a novel tool has become available to study the contribution of blood-brain barrier impairment to disease onset and progression in early stages or pre-stages of dementia,” says Dr Backes.

Although researchers concluded that a compromised blood-brain barrier might be part of events that lead to cognitive decline, this is only a pilot study with a small sample size. Further research is required to quantify these results.

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**WANTED: PARTICIPANTS FOR A 12-WEEK STUDY ON HEALTH AND WELLBEING.**

**DO YOU HAVE EARLY STAGE ALZHEIMER’S DISEASE? ARE YOU OVER 60 YEARS OLD AND NOT EXERCISING REGULARLY?**

If you answered yes to these questions, Dr Shantel Duffy at the Brain and Mind Centre at University of Sydney is looking for participants for a study on overall mental and physical health in adults with early stage Alzheimer’s disease.

You will need to:

- Undergo assessments at the University of Sydney’s Camperdown campus;
- Complete a home-based exercise program; and
- Attend a weekly two-hour group-based education program at the Brain and Mind Centre.

For more information and to participate, contact Dr Shantel Duffy.

Phone: 02 8627 1807
Email: shantel.duffy@sydney.edu.au
Q My mother has dementia and she is becoming very aggressive – even violent at times. Is this normal behaviour for someone with dementia?
People with dementia can have many behavioural changes, and one of the most challenging can be the emergence of aggression. It usually manifests as an expression of fear, anger or frustration. It is important that you work closely with everyone involved – carers, doctors and loved ones – to try to determine why it is happening and what the triggers are. Always speak with their GP or specialist to rule out any physical illness or pain that could be causing the behaviour. You should also make sure that you as the carer are well supported by getting enough time out for yourself and getting enough sleep.

Q I care for my mum who has dementia, and I am always at a loss when she asks for my dad, who passed away more than 10 years ago. What is the best way to handle this situation?
The answer depends on when the person passed away, as you don’t want to re-traumatisse a person with dementia by constantly bringing them back to unpleasant events unnecessarily. Try using the three Rs: respond, reassure and re-direct. Respond to their feelings and acknowledge their concerns. Reassure them by using a short explanation that fits with their thinking. Redirect their attention when and where you can. This might be something simple, such as introducing a new topic of conversation, walking in the garden together or sharing a cup of tea.

For more information or support, contact the National Dementia Helpline on 1800 100 500.

People with dementia under the age of 65 continue to fall between the disability and aged-care sectors.

New research released recently by Alzheimer’s Australia NSW has found that despite significant policy reform in both the aged-care and disability sectors, people with younger onset dementia have fallen through the cracks, with both sectors seeing the other as being better placed to respond.

There are an estimated 25,000 people with younger onset dementia in Australia, and they face very different challenges to those diagnosed with dementia over the age of 65. Many are often still in the workforce, still raising children and financially supporting families, and still paying off mortgages. Alzheimer’s Australia NSW CEO The Hon. John Watkins AM says that although there have been some great examples of goodwill, flexibility and a willingness to help people with younger onset dementia in the disability sector, the division of disability and aged-care eligibility at 65 years of age has, nevertheless, caused immense frustration and difficulties for some caught in the middle.

“While this is a useful distinction for government and policy makers, it has, unintentionally, created a significant issue for many people with younger onset dementia in getting access to and using the services and support they need,” John says.

“Currently, only people who are over the age of 65 can easily access services offered through the aged-care sector, and people with younger onset dementia have felt excluded from this sector.

“This means that people under the age of 65 who have a diagnosis of dementia are funnelled through to the disability sector.

“But limited knowledge and understanding of younger onset dementia, in both the disability and aged-care sectors, has caused a range of issues for people with younger onset dementia.”

John says that it is a complex system and there are no easy solutions.

Although some have great experiences accessing services, that is not always the case.

“We want these great experiences to be the norm. No matter what age you are when you get dementia, you still have the right to access appropriate services and support in a timely manner.

“We have found the Younger Onset Dementia Key Worker Program must be rolled into the NDIS on an ongoing basis to help people with younger onset dementia navigate the system, advocate for their needs and, ultimately, get the help, services and support they need.”

The new research, contained in the discussion paper Younger Onset Dementia: Still Slipping Through the Cracks, also recommends education of NDIS support planners in younger onset dementia, to increase their understanding of the condition and its progression to better serve people with younger onset dementia.

A full copy of Younger Onset Dementia: Still Slipping Through the Cracks can be found at https://nsw.fightdementia.org.au/nsw/research
USE YOUR NOODLE

TAKE A BREAK, HAVE A THINKO! BECAUSE NO MATTER WHO YOU ARE, BRAIN HEALTH MATTERS.

“What occurs twice in a week, once in a year, but never in a day?”

Have we stumped you yet? Then this is perfect timing to introduce you to Thinko! – the ultimate way to exercise six key areas of your brain and tell dementia “game on.”

With our exclusive games, trivia and brainteasers, your frontal lobe and its buddies will be tingling with excitement. Thinko! solo or get a group involved, flex those mental muscles and raise vital funds for dementia support.

Anyplace is a great place to Thinko!. Champion the game online, at home, at your workplace or at your favourite pub. Or simply relax in a comfy chair with a book of new challenges. No matter how you Thinko! your brain will thank you.

HOW TO THINKO!

• Download your daily dose. Thanks to daily doses of Thinko! on your phone, tablet or computer, your brain will feel limber and ready for new challenges. There are new puzzles released every day, so exercise your body’s coolest organ and keep it in top shape.
• Put that competitive nature to good use. Split into two mighty teams and raise funds by powering up for a battle of the brains with family, friends, neighbours, colleagues or even that bloke from the pub. Choose your topics or let us surprise you. With the help of our Thinko! games pack, games nights can be hosted anywhere you like.
• Is trivia more your thing? Looking to get multiple teams of people involved? Register for a Thinko! trivia pack and host a night at your establishment, for your club or just with a huge group of mates. You can carefully select topics to make the masses happy, or let us surprise you with a random selection. From pub trivia nights to a networking luncheon, Thinko! trivia will be a cerebral circus.
• Find your nearest Thinko! event and enter a team. With a range of events happening across Australia, you’ll be able to choose a night of sophistication or go for something a little more casual. The Alzheimer’s Australia NSW team is hosting a star-studded Thinko! event on 1 September. To enquire about tickets, call Rachel on 02 8875 4657.
• Have your Thinko! break old-school by getting yourself a Thinko! puzzle book from our online shop at www.thinko.org.au. Whip out a pencil, find yourself a quiet corner and let your brain work at its own pace.

To solve a Sudoku puzzle, every number from 1 to 9 must appear in:
• Each of the nine vertical columns
• Each of the nine horizontal rows
• Each of the nine blocks.

Remember: No number can occur more than once in any row, column or block. Good luck!

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Access to safe and reliable transport is vital for people with dementia and their carers. Not only does it help them maintain a reasonable quality of life, it also means they can remain living in their community for longer. However, a heavy reliance on cars and driving means people with dementia and their carers could greatly benefit from the proposed changes to the Mobility Parking Scheme and recently implemented alterations to the Taxi Transport Subsidy Scheme. Here’s what you need to know about the proposed changes.

**MOBILITY PARKING SCHEME**

The NSW Mobility Parking Scheme aims to improve access for persons with mobility disabilities. A Mobility Parking Scheme permit may be issued to a person:

- who is unable to walk because of permanent or temporary loss of the use of one or both legs, or other permanent medical or physical conditions;
- whose physical condition is detrimentally affected as a result of walking 100 metres;
- who requires the use of crutches, a walking frame, callipers, scooter, wheelchair or other similar mobility aid; or
- who is permanently blind.

A medical certificate must be provided when applying for a permit. People with dementia meet the first eligibility requirement of having a recognised disability type. However, some people have informed us that their GP has not provided a certificate to support their mobility disability assessment. Alzheimer’s Australia NSW is currently advocating for a broader interpretation of mobility needs that acknowledges cognitive disability.

**TAXI TRANSPORT SUBSIDY SCHEME**

As of 1 July 2016, all Taxi Transport Subsidy Scheme (TTSS) participants will benefit from an increase in the maximum subsidy per trip. This is very welcome news for those who have advocated for an increase for more than a decade. The maximum subsidy will rise from $30 to $60 per trip. When you use the new TTSS $60 docket, you will only pay half of the full taxi fare, or a maximum of $60 per trip, whichever comes first.

If you need further information on how the new TTSS $60 maximum subsidy works, please call the TTSS information helpline: 1800 200 592. You can also find out more at the Transport for NSW website: www.transport.nsw.gov.au/customers/taxis/ttss

**NATIONAL DEMENTIA HELPLINE**

Alzheimer’s Australia NSW provides assistance and advice. The National Dementia Helpline is an Australian Government initiative.

T: 1800 100 500

If there are topics that you would like to have included in future editions, please let Brendan Moore know at: brendan.moore@alzheimers.org.au
I’m a dementia daughter. My mother was diagnosed with Posterior Cortical Atrophy (PCA) in 2013, aged 63. It’s an unusual form of dementia, often described as a ‘visual variant’ of Alzheimer’s because it affects the visual and spatial skills sooner than the memory.

Mum’s diagnosis has changed our family profoundly – our centre of gravity has shifted. Dementia is the subtext for everything we do: daily outings, holiday plans, work routines, living arrangements, trips to the supermarket. Almost every conversation with my father and siblings includes an update on how mum has been today, her latest symptoms or the next step in managing her care.

It has both strained and strengthened our relationships.

We stumbled around for the first year or more – mum’s doctors had given her symptoms a label but hadn’t really provided any other information or service referrals. I spent whole days researching the words that her neurologist had written on a sticky-note. Gradually, we formed a picture of what to expect and found some services available in western NSW.

Mum has handled her diagnosis magnificently, and we’re lucky that now, three years later, her personality and memory are still largely intact. We are also lucky that life in a small town helps mum maintain some independence because someone will always help her cross the road or find the right change in her wallet.

I miss lots of things that mum and I always did together: embroidery, gardening, furniture restoration, shopping trips. We still share our reading via audiobooks. She still gives me great advice and we still laugh a lot. I’m grateful that I live close by, can give practical help and that we spend lots of time together. But I do live in fear of the day she doesn’t know who I am.

Until I was part of a family touched by a dementia diagnosis, I had no idea how little I knew about this collection of diseases. Like most people, I only thought about it in terms of Alzheimer’s disease and memory loss. I hadn’t thought of it as a terminal illness. Also, I didn’t realise how many people I already knew had been touched by it, and I didn’t know it was the second leading cause of death in Australia.

I remain baffled by people’s failure to speak out about this disease. Those who live with dementia should shout to be heard for as long as they possibly can. Families and carers should answer honestly when asked how they or their loved one are faring. Friends should feel able to ask – frankly, but politely – and then listen to the answer. We can’t kill the monster under the bed if we won’t admit it’s there.

Q Why did you become a Dementia Advocate?
I became a Dementia Advocate to give back to Alzheimer’s Australia for the help we continue to receive. I can help raise awareness and advocate for the support needed by people living with dementia. My husband, Rudi, was diagnosed with Alzheimer’s disease in 2013. We knew little about this disease, but the knowledge and skills we acquired through services provided by this wonderful organisation were inestimable. We no longer felt alone.

Q What one thing do carers need to hear?
They need words of understanding and support. These can only come through educating family, friends and the community to remove the stigma and fear of how to communicate with people with dementia. Acceptance and continuing social contact is vital for people living with dementia and their carers.

Q What would you say to someone who wants to be a Dementia Advocate?
I would say, “Don’t hesitate.” There are so many different ways within the Advocates program that you can make a contribution to raise awareness of dementia as a chronic illness.
EDUCATION

ALZHEIMER’S AUSTRALIA NSW COURSES

THE ALZHEIMER’S AUSTRALIA NSW EDUCATION PROGRAM OFFERS COURSES FOR CARE WORKERS, FAMILY CARERS AND VOLUNTEERS.

CARE WORKER COURSES – FEES APPLY

Meaningful Engagement in Activities
North Ryde: 24 August

Working with People Who Have an Intellectual Disability and Dementia
North Ryde: 20 September

A Positive Approach to Understanding Dementia, Effective Communication and Behaviour Changes
North Ryde: 20 October

Communicating with a Person Living with Dementia, Sexuality and Care
Tamworth: 22 November

Experiencing Dementia and Communicating with a Person Living with Dementia
Coffs Harbour: 25 October

Experiencing Dementia and Challenging Perceptions of Behaviour Associated with Dementia
Central Coast: 27 September
Grafton: 24 August

Discover the Person not the Disease and Communicating with a Person Living with Dementia
Forster: 18 October

FAMILY CARER EDUCATION

1 Day Carer Course
Forster: 2 November
Maitland: 25 October
Port Stephens: 16 November
Stroud: 31 August

2 Day Carer Course
Camden: 11, 18 October

3 Day Carer Course
North Ryde: 7, 14, 21 September

4 Evening Carer Course
North Ryde: 7, 14, 21, 28 November
Sylvania: 10, 17, 24, 31 October

Family and Friends
North Ryde: 19 October

Transition into Care
Rosemeadow: 19 August

Understanding Dementia
Tamworth: 23 November

VOLUNTEER COURSES

Interacting with a Person with Dementia
Hamilton: 20 September
North Ryde: 13 October
Port Macquarie: 29 November
Tamworth: 23 November
Taree: 20 October

For more information or to register, please contact:
T: (02) 8875 4640
E: nsw.education@alzheimers.org.au

MEMORY VAN

The Alzheimer’s Australia NSW Memory Van raises awareness of the importance of brain health and provides information on dementia for people living with dementia and their families, service providers and the community.

THE VAN ALSO VISITED:
- Peak Hill
- Lightning Ridge
- Parkes
- Nyngan
- Stroud
- Moama

IN TOUCH SPRING 2016
## COMMUNITY EVENTS

**OPPORTUNITIES FOR PEOPLE WITH DEMENTIA, THEIR CARERS AND FAMILIES TO SOCIALISE, BUILD SUPPORT NETWORKS AND LEARN.**

### CAFÉ CONNECT

- **Bowral**
  - 10.30am – 12pm
  - 15 September, 20 October, 17 November
  - Jane Bushell
  - (02) 4869 5651

- **Bundanoon**
  - 1 September, 6 October, 3 November, 1 December
  - Alison Hall
  - (02) 4869 5651

- **Coffs Harbour**
  - 10 – 11.30am
  - 21 September, 19 October, 23 November
  - Libby Smith
  - (02) 6241 0881

- **Hamilton** (for carers only)
  - 10 – 11.30am
  - 8 September, 13 October, 10 November
  - Belinda Horgan
  - (02) 4962 7000

- **Nelson Bay**
  - 9.30 – 11am
  - 8 September, 13 October, 20 November
  - Miriam Low
  - (02) 4962 7000

- **Newcastle**
  - 10 – 11.30am
  - 19 September, 17 October, 21 November
  - Stuart Torrance
  - (02) 4962 7000

- **Maitland**
  - 11am – 12.30pm
  - 15 September, 20 October, 2 November
  - Stuart Torrance
  - (02) 4962 7000

- **Sutherland Shire**
  - 9.30 – 11am
  - 27 September, 25 October, 22 November (DAM BBQ)
  - Julie Sinnis
  - (02) 9531 1928

- **Queanbeyan**
  - 10am – 12pm
  - 31 August, 28 September, 26 October, 30 November
  - Libby Smith
  - (02) 6241 0881

- **Raymond Terrace**
  - 10 – 11.30am
  - 9 September, 14 October, 11 November
  - Miriam Low
  - (02) 4962 7000

- **Toronto**
  - 10 – 11.30am
  - 25 August, 22 September, 27 October, 24 November
  - Genelle Sharrock
  - (02) 4962 7000

### YOUNGER ONSET DEMENTIA CAFE CONNECT (UNDER 65)

- **Tuggerah**
  - 15 September, 20 October, 17 November
  - Justine Sneddon
  - 0438 715 518

- **Newcastle**
  - 10am – 12pm
  - 7 September, 5 October, 2 November
  - Clare Coyle
  - (02) 4962 7000

### YOUNGER ONSET DEMENTIA SUPPORT GROUPS (UNDER 65)

- **Hamilton**
  - 5.30 – 7.30pm
  - 21 September, 25 October, 22 November
  - Kath Storey or Deb Veness
  - (02) 6584 7444

- **Milton**
  - 10am
  - 21 September, 19 October, 23 November
  - Sandra Kay
  - 0438 702 418

- **North Ryde**
  - 6.30 – 8.30pm
  - 13 September, 11 October, 8 November
  - Lyndell Huskins
  - (02) 8875 4615

- **North Ryde (Daughters & Sons Group)**
  - 5.30 – 7.30pm
  - 13 September, 11 October, 8 November
  - Lyndell Huskins
  - (02) 8875 4615

### CARER SUPPORT GROUPS

- **Corrimal**
  - 10am – 12.00pm
  - 21 September, 19 October, 16 November
  - Val Fell
  - (02) 4229 5926

- **Moruya**
  - 1.30 – 3pm
  - 21 September, 19 October, 16 November
  - Gaye Finch
  - (02) 4474 3843

- **North Ryde**
  - Dinner Group
  - 11 October
  - Kath Storey
  - (02) 6584 7444

- **Laurieton Lunch Group**
  - 14 October
  - Kath Storey
  - (02) 6584 7444

- **Narooma**
  - 10.30a.m – 12pm
  - 15 September, 20 October
  - Gaye Finch
  - (02) 4474 3843

### COFFEE AND CHAT

- **Bega**
  - 10 – 11.30am
  - 7 September, 5 October, 2 November
  - Kylie Ramsay
  - (02) 6492 6158

- **Bateman’s Bay**
  - 10.30am – 12pm
  - 7 September, 5 October, 2 November
  - Gaye Finch
  - (02) 4474 3843

- **Cooma**
  - 10.30am – 12.30pm
  - 27 September, 25 October, 22 November
  - Libby Smith
  - (02) 6241 0881

### SPRING 2016 IN TOUCH CALENDAR

- **Springfield, Toowoomba**
  - 10am – 12pm
  - 15 September, 20 October
  - Gaye Finch
  - (02) 4474 3843

- **North Ryde (AD-HOC Group)**
  - 1pm
  - 24 September, 29 October, 3 December
  - Marina Agostino
  - (02) 9888 4268

- **Pambula**
  - 10am – 12pm
  - 27 September, 25 October, 22 November
  - Nola Hergenhan
  - (02) 6492 6158

- **Scone**
  - 10.30am – 12pm
  - 27 September, 25 October, 22 November
  - Miriam Low
  - (02) 4962 7000
Members of the Coalfields branch of the American Motorcycle Club of Australia hopped on their bikes to raise funds for Alzheimer’s Australia NSW and dementia research.

The inaugural Dementia Run in the Hunter was held on 30 April. Club president Michael Wheatley came up with the fundraising idea because, like many, his family has been touched by dementia: his grandmother had Alzheimer’s disease and his mother currently has the illness. Michael is passionate about raising awareness and supporting the Hunter region to grow to meet increasing demand for services. Roughly 280 bikes and more than 550 people came to show their support and participate in the ride. There was breakfast, a bike and car show with prizes, live music and a BBQ dinner in the town of Greta as well.

Club members and the community came together to make the day a success; more than $30,000 was raised for the Hunter Dementia and Memory Resource Centre in Newcastle.

START YOUR ENGINES

WHO SAYS YOU NEED TO WALK OR RUN A 5K? ONE MOTORCYCLE GROUP DECIDED TO PUT THEIR OWN UNIQUE SPIN ON IT.

Stronger Together

After four women in her family were diagnosed with Alzheimer’s disease, one woman said ’enough’.

Four generations in Jodie Pophristoff’s family – her great-great-grandmother, great-grandmother, grandmother and mother – all have or had Alzheimer’s.

"Mum was diagnosed youngest out of the four of them, officially at age 60," Jodie says. "Each woman had their daughter care for them until their last days. I was luckiest of all the women, as I had studied dementia in the hope of working in aged care but ended up with the loveliest patient: Mum.

"I was always confident caring for Mum, but on the tiring days I would call the Alzheimer’s Australia National Dementia Helpline. The people on the phone were wonderful and always assured me I was doing great and offered sound advice."

After her mother recently passed away, Jodie decided to organise a community fundraiser for Alzheimer’s Australia NSW.

"In the later stages of Mum’s Alzheimer’s, my hair was getting really thick and long. I really needed a haircut and one day Mum said, ’If you want to cut it all off you could raise some money for Alzheimer’s, I’d love that’!"

Her crop raised more than $6500 for Alzheimer’s Australia NSW. Jodie also reached out to local businesses for donations and raffle prizes. "A huge number of people I approached said yes and donated goods for the raffles and lucky door prizes,” she says. “Leading up to the day, I was overwhelmed by people being so lovely and giving, and the bowling club where it was held was amazing.

“It isn’t difficult to make a difference,” Jodie adds. “A lot of people had no idea that anyone could develop dementia, and they thought it was a natural progression. Many found the stats shocking and were keen to help. Everyone who wants to help make a positive change has that power.”
WE OFFER OUR CONDOLENCES TO THE FAMILIES WHO HAVE LOST THEIR LOVED ONES. WE ALSO THANK THEIR FRIENDS AND FAMILIES WHO HAVE DONATED TO ALZHEIMER’S AUSTRALIA NSW.

**A**
- Halina Arter

**B**
- Robert Bruce Bailey
- Kevin Paul Barnett
- William John Brown
- Laurie Burns

**C**
- Carmelo Catanzaro
- Paul Michael Crump
- Violet Cummings

**D**
- Antonio D’Agostino
- Ron Davis
- Maria Duggan

**E**
- Beryl Dawn Evans

**G**
- Monica Gibbons
- Giuseppe Giorgianni
- John Gunning

**H**
- Kathleen Mary Handley
- Brian Donald Hawkins
- Percival Hilliar

**K**
- Mebra Kakaire
- George Kappas
- Gunda Klavins

**L**
- Gaetano Lasorsa
- Mary Ethel Lomas

**M**
- Dimitrije Maksimovich
- Bruce Manchester
- Sybil Manton
- Marcia Mason
- Steve James Masselos
- Brian Matthewson
- Maurine Patricia Mawbey
- Assunta Merenda
- Robert James Mirow

**O**
- James Joseph O’Donnell

**P**
- Louis Lawrence Palmier
- Peter Papadopoulos
- Peter Pappas
- Anna Maria Puglisi
- Jean Robb

**S**
- Ronald Saddler
- Vanda Salotti
- Norman Stafford
- Simpson
- Paul Sterling Sinclair
- Adam Augustus
- Smeulers
- Kenneth Smith
- Netta Sultana
- Magdalini Sykiotis

**T**
- Robert Michael Tate
- Arsenia Torres
- Despina Tourvas

**W**
- Kevin Patrick Ward
- Valerie Webeck
- Norma Fay Whitby
- Barbara Dorothy Wiley
- Peter Willing
- David Vivian Wilson
- Norma Challis Wilson
- Kenneth Woolfenden

Alzheimer’s Australia NSW would like to acknowledge and thank the families and executors of the recently received bequests from which people with dementia, carers and their families have received lasting benefit.

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**DEMENTIA CARING**

**Specialist Home Care & Day Centres**

**SPECIALISED HELP FOR YOUR FAMILY**

**EALY STAGE CARE**
- Support in caring and delaying onset of dementia.
  - General support at home
  - Mind exercises and games

**MIDDLE STAGE CARE**
- Home organisation
- Dressing, bathing, cooking, feeding
- Helping with complex care needs

**LATE STAGE CARE**
- Around the clock 24/7 specialised care
- Professional respite services and advice

**Why clients choose our Specialist Services**
- We Provide Relief from the strains of caring for a loved one
- Day Care Centres provide social and support activities
- Specialised Dementia Advice delaying the need to move into a nursing home

LIBRARY RESOURCES
THE ALZHEIMER’S AUSTRALIA NSW LIBRARY OFFERS FREE LOANS OF BOOKS, DVDS AND OTHER RESOURCES TO MEMBERS THROUGHOUT THE STATE. HERE ARE REVIEWS OF SOME OF THE ITEMS CURRENTLY AVAILABLE.

One Day at a Time: Sharing life with dementia by Dorothy Webb
Care partners are the essential ingredient in the life of a person diagnosed with dementia. They enter this new role unexpectedly, untrained and totally unprepared for their own mix of emotions. In her first book, author Dorothy Webb shares insights on how to cope, live and laugh as a carer of a person with dementia to help family, friends and the community realise the emotional trauma of the early years as a carer.

Vivienne Boyd, Education Co-ordinator

In-home Dementia Care Tips and Techniques by Teepa Snow
Teepa Snow is one of America’s leading educators on dementia. This DVD focuses on in-home care, the situations and challenges carers face, and the things that cause distress and how to deal with them. Her concern for the wellbeing of carers is evident, as she gently leads them to understand and accept that there is no cure for dementia. It is for carers to nourish themselves, because otherwise how can they be expected to take care of anyone else? “Life does not stop because of the changes experienced when caring for a loved one with dementia,” she says. “This will help you make it through and will honour you and them.”

Janet Godsell, Diversional Therapist and Carer Support Group Leader

Ten Thousand Joys and Ten Thousand Sorrows: A couple’s journey through Alzheimer’s by Olivia Ames Hoblitzele
If you have ever wondered what the experience of living with dementia would be like for experienced meditators, this is the book for you. One couple recounts their experience with dementia and the benefits of meditation for both carers and those living with a diagnosis. Readers will be inspired by the couple’s capacity to continue living with a sense of purpose, learning and personal growth throughout the course of the disease and heartened to know that it is possible.

Marg Coults, Dementia Advisor

Dementia Support for Family and Friends by Dave Pulsford and Rachel Thompson
When you have a family member who is diagnosed with dementia or Alzheimer’s disease, you are left in shock, and lost as to what information is helpful. This is the book that all doctors and professionals should recommend to family and friends to read. It answers a lot of questions that people might have, but are too overwhelmed to ask. Unlike a lot of books that focus on the early or late stages of dementia, this one takes a close look at what happens in the middle. Not only is this book written in a friendly, supportive, and realistic way, but it feels like a wise friend who is there to guide you through each step of the way.

Michelle de Mari, Coordinator, Library and Information Services

To Love What Is: A Marriage Transformed by Alix Kates Shulman
This memoir is a love story. The writer shares the tumultuous events that result when her husband, who has early signs of dementia, suffers severe brain damage after a fall. Within the changed circumstances of their lives there is much sadness and despair at times, but this is countered them striving to live fully as a couple and as individuals. They are forced by the new reality of ‘what is’ to redefine their relationship. The title conveys the strength of her determination; at first with her husband’s needs being paramount and then, finding a precarious balance, as she rediscovers her own life.

Michelle de Mari

LOANING ITEMS
These items and more are available to members of Alzheimer’s Australia NSW, and can be found at local resources centres and offices. Resources can also be posted to you. Find a list of offices and resource centres on the Alzheimer’s Australia NSW website.
T: (02) 9888 4218
E: nsw.library@alzheimers.org.au
W: nsw.fightdementia.org.au/nsw/about-us/contact-us